Protestant perspectives on end of life care

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Abstract: This book examines the ethics of end of life care, focusing on the kinds of decisions that are commonly made in clinical practice. Specific attention is paid to the intensification of treatment for terminal symptoms, particularly pain relief, and the withdrawal and withholding of care, particularly life-saving or life-prolonging medical care. The book is structured into three sections. The first section contains essays examining end of life care from the perspective of moral theory and theology. The second sets out various conceptual terms and distinctions relevant to decision-making at the end of life. The third section contains chapters that focus on substantive ethical issues. This format not only provides for a comprehensive analysis of the ethical issues that arise in the context of end of life care but allows readers to effectively trace the philosophical, theological and conceptual underpinnings that inform their specific interests. This work will be of interest to scholars working in the area as well as clinicians, specialists and healthcare professionals who encounter these issues in the course of their practice.

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Chapter 9
Protestant Perspectives on End of Life Care

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Abstract

Protestantism is generally known for holding a variety of different positions, especially when it comes to moral issues. Concerning end of life care, though, there are some guiding ethical principles held by most Protestant Churches: human life is a gift of God and must, therefore, be protected; humans are created to live their life freely in responsibility before God and other human beings; and Christians are called to love and care for those in need, e.g. for ill and dying persons. This chapter discusses these guiding principles and their theological foundation. We also examine the conclusions European Church papers have drawn from these guiding principles for care at the end of life. Particular attention is paid to church perspectives on the withholding and withdrawing of life sustaining medical treatment, Advance Directives, decision-making in end of life care, and palliative care. We conclude that the positions of the Protestant European Churches on these issues are, for the most part, in line with leading secular positions in the field of medical ethics.

Keywords: Christianity; Protestant; End of Life; Care.

Ethics in Protestantism

Protestant Churches are generally known for the plurality of the positions they hold, especially when it comes to moral questions. This is due to the fact that Protestant Churches rely on an ongoing process of interpretation of the biblical scriptures which is not unified in a hierarchic magisterium. The ongoing nature of Protestant moral discourse leads to different understandings of how to interpret the biblical scriptures in the present. Accordingly, there are numerous Protestant Churches and all of them are organized differently.[1]

The reason that a plurality of positions can be found within Protestantism becomes obvious when dealing with moral issues. At the centre of Protestantism is a certain understanding of God's redemptive act through Christ which is spelled out in, for example, the doctrine of justification. Crucial to this Protestant understanding of redemption is that it relies on faith alone. Faith is not defined by (morally) good actions, but is understood as involving trust and affirmation of God's promise of forgiveness. Thus, there is little necessity for a unified teaching on moral issues in most cases, because it does not touch the centre of faith in a Protestant understanding. There is, however, little doubt that living in faith can and should have an impact on the moral orientation and the actions of Protestant Christians. Therefore, ethical reflection on moral implications of Christian faith is a necessary task and, accordingly, Protestant Churches and Protestant theology engage in a range of ethical discussions including those that concern end of life issues.

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[1] The Council of Protestant Churches in Europe (CPCE) e.g. counts 105 member Churches, and not all Protestant Churches in Europe are members of the CPCE.

The process of interpreting the scripture is in itself a task of theological reflection. Theological reflection is crucial to a Protestant understanding of Church, but does not itself define the Church's teaching. In most Protestant Churches, the power to teach resides with Synods which are elected Church Parliaments. How often they use this power to teach varies between the different Protestant Churches. There are only a few mandatory decisions of Protestant Synods in Europe concerning ethical questions on end of life care. These include: the decisions of the general Synods of the Protestant Church in Austria in 1996 (EKÖ 1997); the United Protestant Church in France in 2013 (EPUF 2013) and the General Synod of the Church of England in February 2012 (Church of England 2012: 14-34). If they engage in these public discussions at all, rather than providing a definitive view, most Protestant Churches publish discussion papers, opinions or orientation aids (in the following generally referred to as "papers") that lay out the relevant theological and ethical arguments concerning a controversial topic. The primary aim of these papers is to enable Protestant Christians to come to their own moral conclusions and to make their own individual judgements. They do not aim at formulating a doctrinal position of the Church.

Often, a second aim of such papers is to promote in further public discourse and to engage in or with political processes of decision-making. The Protestant Churches in Europe differ in the way they engage in and with public discourse on moral matters. There is a strong tradition of engaging in public debates in the Protestant Church of Germany (Evangelische Kirche in Deutschland: EKD), the Swiss Protestant Church, the Lutheran Church of Austria, the Protestant Church of the Netherlands and the Anglican Church. The Schottish Episcopal Church also publishes a series of essays on current issues of Christian faith. However, other Protestant Churches in Europe engage in public discourse only occasionally; some do not publish opinions or orientation aids at all, and some restrain themselves from public debates, almost entirely, preferring to focus on matters of faith and Church life.

Guiding principles and their theological foundations

Where Protestant Churches have published on ethical issues at the end of life, they have been primarily occupied with highly controversial issues such as (physician) assisted suicide and euthanasia (e.g. SEK 2010b; Church of England 2012; EPUF 2013; EKD 2007). Only a few Protestant Churches have published papers on clinically important and less controversial issues such as withholding or withdrawing treatment and palliative care (EKÖ 1997; SEK 2006; 2010; EKD 1989; 2002; 2005; PKN 2006).[2] One of the most important Protestant Church papers dealing with these issues is the orientation aid "A Time to live, and a time to die" by the Council of Protestant Churches in Europe (CPCE 2011). The CPCE does not have

[2] A helpful collection of Church opinions concerning end of life issues is Schardien (2006). Concerning older Church papers we partly rely on this collection (and its German translations), but have also included some more recent publications of Protestant Churches in Europe. For a regularly updated overview on papers of German Protestant Churches on issues of medical ethics cf. www.ev-medizinethik.de. Concerning the position of the Church of England we partly rely on the overview of McCarthy (2014).

any teaching authority and is not itself a Protestant church, but an umbrella organization of Protestant Churches[3] in Europe who have signed the Leuenberg Agreement.
A comparison between this orientation aid and different papers of the member Churches of the CPCE and of other Protestant Churches in Europe such as the Church of England, shows that – despite the Protestant reputation of pluralism – there is a shared consensus on most of the issues discussed. Thus, what Brendan McCarthy writes about the Church of England might as well be said about Protestantism in Europe in general: "It is not possible […] to present a definitive Christian, or even Church of England, perspective on medical ethics, but it *is* possible to identify a number of commonly agreed features that contribute, consciously or subconsciously, to the perspectives many Church members hold" (McCarthy 2014: 3). McCarthy distinguishes between the core beliefs of Christian faith and the guiding (moral) principles which are derived therefrom, and which are expressed in particular policies and practices of the Churches.

Investigating the different Protestant Church papers concerning end of life issues (including those on questions of euthanasia and assisted suicide), one can identify these common core beliefs, and the guiding principles of Protestant ethics:

Intrinsic dignity: Human life is created by God in his image and therefore has an intrinsic dignity (CPCE 2011: 33; EKD 1989: 39f; EPUF 2013). Thus, Christians are obliged to protect human life (CPCE 2011: 38; EKÖ 1997: 7; EKD 2002: 18, 35; PKN 2006: 19; SEK 2007: 20f; Church of England 2012: 35; McCarthy 2014: 6) (s. 2.1: Valuing life as a gift of God).

Freedom and dependency: Human life is lived in response to God's creative and redemptive action. This entails the freedom to lead one's own life in responsibility before God (CPCE 2011: 35–38; EKD 2005: 14f; PKN 2006: 18; SEK 2007: 21f; McCarthy 2014: 15). At once, every human being is dependent on God and other human beings. Thus, there is always a continuum of being autonomous and dependent – human beings are never only one but always both (CPCE 2011: 33–35; EKÖ 1997: 8; EKD 2005: 14; SEK 2007: 21f). Humans are thus genuinely social beings (CPCE 2011: 35; EKD 2002: 18; McCarthy 2014: 14f). As human life is created as life in relations, autonomy can only be realized by respecting the relations human beings live in and by (s. 2.2: The freedom of the Christian).

Duty to care: There is a Christian duty to care especially for vulnerable individuals, such as those who are ill and/ or dying. This is a specification of the Christian duty to love the neighbour (CPCE 2011: 39–42; EKD 2005: 14; PKN 2006: 17f, 18f; SEK 2007: 25f; EPUF 2013; McCarthy 2014: 13f) (s. 2.3: An ethics of love and care).

According to the CPCE orientation aid the focal point of these guiding principles is the regard for the patient (CPCE 2011: 42): The patient as a suffering human being is the neighbour to whom Christians owe love and care. This includes attentiveness to the individuality

[3] The same applies for the Protestant Church of Germany (EKD) which is an umbrella organization of 20 independent Protestant Churches in Germany. The most important German Protestant Church papers on medical ethics have been published by the EKD and not by its member Churches. Therefore we refer to these publications.

of the person and his situation, and thereby sets moral context (CPCE 2011: 43; EKD 2002: 14; SEK 2007: 22): Morality is not an end in itself, but the main task is care for the neighbour in need (CPCE 2011: 42; cf. SEK 2007: 25), implying protection (of life) and respect for individuality.

The Church papers on end of life care do engage in a process of weighing the different moral goods and duties (i.e. the guiding principles), that are rooted in biblical texts, and a theological tradition of interpreting the biblical texts (core beliefs). We will now first discuss the mentioned theological foundations and then draw some conclusions concerning the end of life care.

Intrinsic Dignity: Valuing life as a gift of God and the ambivalence of death

The duty to protect human life and the weight given to this duty is characteristic of a Christian approach towards end of life care. Christianity does share with all monotheistic religions the belief that the world is created by God and the conviction that the creation is good. According to the biblical book of Genesis, God gives the breath of life (Gn 2:7). Living nature is, then, a good gift of God, one that is worthy of being protected. Therefore, "life" is not a morally neutral concept, but always comes with a positive evaluation: Life is good because God created it.

Accordingly, the concept of death as the negation of life comes with a predominantly negative evaluation; it is seen as the enemy of life. This also applies to the Christian hope for resurrection, because resurrection does not change the evaluation of death. Rather it is about hope for the victory of life over death brought about by God himself (cf. e.g. 1. Cor 15: 54-57). Thus, both the doctrine of creation, and the doctrine of salvation by death and resurrection of Christ imply a positive evaluation of life and a negative evaluation of death: God wants life and not death. The negative evaluation of death implies a prohibition of killing. This applies to human beings in particular, as they are created in the image of God (Gn 1,27) and since it is the human being to whom God himself gives the breath of life (Gn 2:7). The specific moral status of human life in the biblical tradition is observable at the end of the narrative on the Noachian deluge when God allows the killing of animals for consumption, but generally prohibits the killing of humans, explicitly because they are created in the image of God (Gn 9,3).

One should nevertheless be careful when drawing conclusions concerning the end of life care: The negative evaluation of death as a result of human action in the Old Testament does not lead to a complete prohibition of killing (Hossfeld 2003: 22f). There are certainly arguments available, but one cannot argue for a categorical prohibition of killing by reference to biblical texts alone. Certainly, God desires men to live and not to die (Hossfeld 2003: 23f). Therefore, the biblical tradition is such that there is a clear tendency towards the view that the death of a human being is generally undesirable, and so is killing. That said, there are also biblical texts that understand death as part of the creaturely reality of finite human beings: Man has not been created as an infinite, but as a finite creature (Ps 104: 29, Ps 146:4, Jb

34:14f, Ec 12,7; cf. Fischer 2011). One cannot have (human) life without death. Thus, alongside a general negative evaluation of death, there is at least a neutral evaluation which recognises death as the determined end of human life. This ambivalence of death has been extensively discussed in Protestant theology (cf. e.g. Barth 1960: 559–565; Jüngel 1971: 91–120; Pannenberg 1994: 265–275; Springhart 2016: 30–71).

Biblical texts provide for a distinction between death as something happening to human beings (e.g. death due to illness) and death as something brought about by human beings (e.g. by killing or suicide). In the first case, death can be understood as the result of life's finiteness, and therefore primarily as a result of God's will to create humans as finite beings. In such cases death can be accepted as determined by God. In the second case, death is primarily the result of human actions and the Christian must consider if this action is congruent with the belief that life is a gift of God, something that only God himself can take back. When it comes to medical ethics, this theological distinction allows us to distinguish situations in which medical treatment might be withheld or withdrawn from those in which death is being hastened e.g. euthanasia or assisted suicide. Decisions to withhold or withdraw life sustaining medical treatment can be theologically understood as involving an acceptance of the time of death as determined by God, while the latter examples involve causing death to occur and thereby determine the time of death.

Freedom and Dependency: An Ethics of responsibility

During periods of illness, and in other situations in which life is dependent on medical treatment, the crucial theological question is: Who has the right to interpret whether this is a situation of the predetermined end of life or not? Within Protestant theology there is a large consensus that this question can only be answered by the person affected. The freedom of the individual at the end of life resides in how a person interprets his or her own situation of illness: as a situation of dying or not (Fischer 2005: 355-357). If someone interprets their illness as dying, then he or she has the right to accept it as such, and his or her right to no longer fight death must be accepted by others. Consequently, any life prolonging medical treatment should then be withdrawn.

In a Protestant theological perspective, the concept of individual freedom is not about the sovereignty of the individual, but about their responsiveness (Dabrock 2007; Coors 2014). To act and to choose freely is to respond to situations and opportunities that one has not chosen but is dependent on.[4] This dependency does not exclude freedom, but freedom of the individual is to be defined within the boundaries of human dependencies. Theologically speaking, the dependency is already entailed in being created and in being in need of reconciliation with God and men.

Protestantism is widely known for its emphasis on the freedom of the Christian, because both the reformation and especially Martin Luther laid great emphasis on it. According to Luther,

[4] Therefore, Protestant Theology can embrace the philosophical concept of humans as "dependent rational animals" (MacIntyre 1999).

God freed the individual from the rule of sin, and faith means to trust in this act of God (Luther 1897). Therefore, to have faith means to trust in a freedom dependent on the grace of God. A crucial point of the Lutheran concept of freedom thereby is about freedom not only being "freedom from …" (negative freedom), but also about being "freedom to …" (positive freedom). Thus Christian freedom has an aim, it is freedom to love the neighbour. The freedom of faith is about abolishing the rules of (moral) law, but at the same time it aims at their fulfilment by enabling the individual to love and care for those who are in need.
20th century Protestant theology, especially in Germany, has interpreted this close relation between freedom and love by means of the concept of responsibility (Bonhoeffer 1959; Toedt 1988; Dabrock 2009). Christian freedom is the freedom to lead one's own life in responsibility before God and the neighbour. Individual freedom is, therefore, always communicative freedom (Huber 2012): It is not realised by distancing oneself from others but by responding to God and to the social community one lives in (Dabrock 2007; Coors 2014). To live a free life means to relate oneself to given (social) goods (Anselm 2015; on the importance of *social* goods cf. MacIntyre 1999). In a Protestant perspective, freedom is only realised in, by and through communicative relations to others. This entails that ethical reflection should not only focus on the individual's decision-making but also on the social context and goods it is framed by. Therefore, ethical decision making at the end of life needs to be considered as a communicative process.

Duty to care: an ethics of love

Christian freedom is not only a response to the social goods one is confronted with, but it is – as pointed out above – a freedom to love the neighbour. The basic biblical parable of the Good Samaritan (Lk 10:25–37) shows that loving the neighbour is not about loving those who happen to be close to us, but about supporting those in need of help. The crucial question of this parable is not "Who is the neighbour I am obliged to help?", but it is instead: "Which of these three, do you think, proved neighbour to the man who fell among the robbers?" (Lk 10:36). Phrased differently: "Who is the person in need whose neighbour I am obliged to become?" Thus, a Christian ethics of love is an ethics of care for those who are in need – be it due to social exclusion, poverty, illness or disability. Certainly, ill and dying patients are persons in need. Therefore, there is an obligation to care for them and help them. This Christian spirit of love and care has inspired a long history of charitable work, reaching from the founding of the first hospital-like institutions in the 4th century to participating in institutions of modern social health care systems (Ferngren 2009: 124–130; Hammer 2013). In the 20th century the idea of hospice and palliative care as developed by Cicely Saunders was inspired by a Christian ethics of care for the most vulnerable, i.e. the dying patients.

In its ethical dimension, the Christian concept of love for the neighbour strongly resembles the concept of care as it is discussed by care ethicists like Gilligan (2003), Noddings (2013) or Held (2006). These ethicists have argued for an ethics based on caring relations (Noddings 2013: 51) as opposed to a concept of ethics primarily built on the idea of rights (Gilligan 2003: 132, 136) or an ethics based on categorical principles (Noddings 2013: 25). Similar to Protestant Christian ethics, there is an emphasis on the relations between persons and on the responsibility to care for those one is related to. However, in the Christian perspective, love

for the neighbour is – as much as love for oneself – rooted in the love of God: "The dynamic of life is fuelled by one stream of love: I receive the goodness of life; I gladly affirm it by saying ye to myself; and I pass this affirmation on to others" (de Lange 2015: 35). Very similar to care ethics, de Lange concludes that a "love ethics, therefore, implies that we enter into the dynamics of relationships that cannot be governed by absolute principles such as autonomy or paternalism. It implies negotiation and adjustment in a never-ending search for the good" (de Lange 2015: 59).

The ideal of loving your neighbour, thus, entails that each moral problem must be discussed on its own account: What is "good" to the person in need? This question cannot be answered without respecting the individuality of the person, which necessitates communicating with them about their interests, and it cannot be answered without caring for him or her (Noddings 2013: 14, 24). Thus, moral principles like respect for autonomy and beneficence remain important. A Christian ethics of love, though, will emphasize that applying those principles wisely relies on the "concern […] for the good of others, for their own sake". This is how de Lange (2015: 47) theologically defines love.

Thus, loving the neighbour is where ethical deliberation begins: If one does not love the other, if one does not care, there is no ethical problem at all, because there would be no responsibility. However, if someone cares for persons in need, he or she has to ask himself what he owes to the dying person and what one is obliged to do in face of the patients' needs. In this sense, love and care are not simply moral principles or duties, but they are at the very foundation of morality. Accordingly, Christian faith can be understood not only as giving moral orientation, but as providing motivation to engage in ethical deliberation on moral questions.

Ethical decisions concerning the clinical practice

These guiding moral principles can inform moral questions that concern the clinical practice of end of life care. We will have a closer look at four crucial issues and the way in which they are discussed in different Protestant Church papers. These are: the withholding and withdrawal of treatment (1), advance directives (2), decision making in end-of-life issues (3) and palliative care (4).

The withholding or withdrawing of treatment

There is a clear consensus within the protestant Churches that the duty to protect human life does not entail prolonging life as long as medically possible (CPCE 2001: 46; PKN 200: 21f; EKD 1989: 106; EKD 2002: 34f; 2005: 12f; EKÖ 1997: 10). Therefore, withholding medical treatment may be morally acceptable in cases where the quality of life of a patient is not improved by medical treatment, especially if it merely postpones death or slows the process of dying in patients with a low quality of life (CPCE 2011: 49f). The Protestant Churches do emphasize, though, that quality of life does not simply mean the greatest possible autonomy. Having a good quality of life is compatible with being dependent on others. The emphasis on

life having a quality even in a merely passive existence derives from the theological evaluation of human life as a gift of God and from the understanding of freedom as being congruent with dependency, as discussed above. Accordingly, life can have a quality even if it "does not possess features such as control, intentionality, rationality or subjective activity" (CPCE 2011: 51; cf. PKN 2006: 19; EKD 1990: 41).

So the message is twofold: On the one hand, it can be legitimate to withhold or withdraw treatment because the quality of life cannot be sustained in spite of medical treatment, the latter possibly even being a harmful overtreatment of the patient (CPCE 2011: 54f). On the other hand, the criteria by which a judgement about the quality of life of a person is made must be considered carefully. Focusing only on how far someone can actively participate in daily life is not acceptable in the Christian perspective; the value of individual life does not reside in what an individual can give to the community, but in being created in the image of God. Therefore, the quality of life argument for withholding or withdrawing medical treatment must consider whether "in a given medical situation a human being's condition is not improved [or maintained], but in fact worsened by receiving a certain medical treatment" (CPCE 2011: 49). It is about balancing out harm and benefits for the patient.[5]

The evaluation of treatment as being harmful or beneficial to an individual's situation also has to do with asking for the patient's views and considering their will. Thus, Protestant Church statements are in accordance with one of the key features of medical ethics: informed consent. A Protestant Christian position can support the position that no one should be treated against his or her will (CPCE 2011: 55; EKD 2005: 15; SEK 2010: 32), as long as the person deciding is informed about the implications of the decision and has the capacity to decide (CPCE 2011: 56). The will of the patient must be respected, even if the consequence will be his or her death (CPCE 2011: 56). This is in accordance with how most European countries legally deal with end of life decisions. Protestant Church statements support the right of the individual to reject medical treatment – even if it is life-sustaining – based on an informed decision. As mentioned above, this individual freedom includes the freedom to interpret one's own situation of illness as process of dying or not (EKD 2005: 16; CPCE 2011: 37f).

Advance Directives

Whilst the argument concerning the patient's current will is clear, certain difficulties arise in dealing with situations in which the patient is incapable of explicating his or her will themself. The CPCE orientation aid reflects the different legal regulations concerning advance directives in Europe,[6] as well as the different positions within Protestant Churches: The CPCE orientation aid agrees on a minimum, which is that advance directives "should have considerable weight regarding life-prolonging treatment" (CPCE 2011: 57). However, not all Churches consider Advance Directives as expressing legally binding decisions of the patient.

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5 For further discussion of this issue see chapter 13 The Distinction between Ordinary and Extraordinary Treatment by Kearns, Emmerich and Gordijn.

6 For further discussion of differing legal frameworks and their national contexts in Europe see Horn, Chapter 18, this volume.

The reasons for this are not primarily theological. Rather, there are general doubts about the possibility of deciding about medical treatments in advance: "Can individuals know beforehand how they will experience a life in such a state, and can they know what their central values and wishes will then be?" (CPCE 2011: 59).

The paper of the German Protestant Church on Advance Directives (EKD 2005) discusses two positions which seem to be representative of the ambivalence within Protestant Church papers on this issue. This discussion concerns balancing the duty to protect human life (as something created and given by God) and the duty to respect the individual freedom of each person. Those arguing in favour of a restriction of Advance Directives to situations of imminent death give more weight to the argument of life-protection: Death has to be awaited as a fate, and individuals should only be allowed to decide in advance about the withholding or withdrawing of treatment for situations of imminent death (EKD 2005: 19f). Those arguing against any restrictions for Advance Directives argue that, as informed consent always is obligatory for medical treatment, this should also apply for possible future treatment options (EKD 2005: 20f). Thus, respecting the patient's individual freedom gains weight.

Decision-making in end-of-life care

In accordance with the guiding principles formulated above – that "human life is lived and thrives through relations" (CPCE 2011: 35) – the involvement of the patient's family is emphasized by some of the Church's papers (CPCE 2011: 59; EKD 2005: 13f). As autonomy in a Christian perspective is only realized through social relations, processes of decision-making need to take the relational constitution of human beings into account: this applies to situations of decision-making, if persons are not able to consent or are incapable of stating their own will. In this case, the emphasis on relationality argues in favour of including relatives (or patients' advocates, representatives or guardians) in the decision-making process. The CPCE decision aid (CPCE 2011: 59) even discusses in how far the interests of the patient's family – such as having time to adapt to the situation– must be considered. Yet, there is no doubt that the autonomous decision of the patient ought to be respected in the end. Again, a weighing of moral goods is necessary: There is on the one hand side the good of the relationships by means of which the personal identity is constructed, and on the other hand side the good of protecting relatives who potentially suffer and feel insecure about making decisions concerning treatment withdrawal. Since relatives of a dying person are also in need of care, they should be supported when caring for their dying relative (EKD 2005: 13).

Concerning Advance Directives, the emphasis on the social dimension of ethical decision-making leads to the recommendation to talk with relatives and friends, as well as physicians and chaplains, when reflecting considerations written down in an Advance Directive (EKD 2005: 13).

Palliative Care

As caring for those in need is a central Christian value, it is only consistent that the CPCE, like other Protestant Churches (EKD 2002: 36; SEK 2006 and 2010; PKN 2006: 22), encourages further implementation of palliative care for seriously ill patients. The CPCE acknowledges that "effective painkilling treatment is unlikely to have a life shortening effect" (CPCE 2011: 65) and that the decision for a continuous deep sedation at the end of life is not a termination of life and therefore is acceptable (CPCE 2011: 66). The Protestant Church of the Netherlands (PKN 2006: 23) discusses the problem of distinguishing palliative sedation from euthanasia in more detail and emphasises that a life-shortening side effect of sedation is acceptable, but that the hastening of death should never become the aim of treatment.[7]

The Swiss Protestant Church engages in a discussion of some of the ethical issues that arise in the context of palliative care in some detail (SEK 2006 and 2010). These papers go beyond the usual discussion about palliative sedation and euthanasia. The SEK understands palliative care as a process of caring that is in line with a Christian sense of treating ill and dying persons (SEK 2006). If palliative care is seen this way, it is more than a medical task: it is a way of caring for the person including his whole individual biography. As such, interdisciplinary work is needed: reducing palliative care to a mere moderation between the different health care disciplines would miss its potential (SEK 2010).

Conclusion

The positions adopted by the Protestant Churches in Europe are guided by a theological understanding of human beings as dependent on God's creative and redemptive actions but, at the same time, as being called to freely respond to God's action by responsibly leading their own life as part of the human community. Notwithstanding the inherent plurality of Protestantism and Protestant theology, there is a large consensus on the ethical issues we have discussed. However, dissent can still be found concerning other issues and not all Protestant Christians will agree with the official positions held by their Church. The papers discussed are not official teaching of the church. They aim at formulating relevant theological positions and arguments so as to inform the individual ethical judgments of each protestant Christian. These Protestant positions and arguments concerning end of life care are to a large extent in accord with positions generally held in the field of medical ethics.

Protestant Churches accept the possibility of withholding or withdrawing life sustaining treatment either because of a lack of (or even negative) effects of the treatment on the patient's quality of life or because of the patient's will. If the patient has given their informed consent their will must be respected. It is also beyond doubt that Advance Directives are important to decision making with regard to incapacitated patients. Some protestant churches do accept Advance Directives as obligatory and binding. The decision making about medical treatment options should involve family and representatives of the patient. There is a basic duty to care for the patient and to respect his or her individuality. This duty does not end if the patient is

[7] For further discussion of the ethical questions that arise in relation to Continuous Deep Sedation see Holm, chapter 17, this volume.

dying, but results in the necessity of good palliative care understood as an interdisciplinary, competent care for the patient and his family.

Probably the most important aspect of the Protestant Christian perspective is the emphasis on the situational ligation of love and care. A Christian ethics in a Protestant perspective is not primarily about following ethically reflected and morally correct rules or principles; it is about caring for those in need. This attitude is shared by Protestant Christian ethics and the ethics of care.[8] This does not mean that Protestant Christian ethics is without rules or principles, but that these only have an auxiliary function for moral behaviour. Christian morality rather is about how to live by moral rules in a spirit of love and care.

Abbreviations

CPCE Community of Protestant Churches in Europe
EKD Evangelische Kirche in Deutschland (= Protestant Church of Germany)
EKÖ Evangelische Kirche Augsburgischen und Helvetischen Bekenntnisses in Österreich (= Protestant Church of Augsburgian and Helvetian Confession in Austria)
EPUF Église Protestante unie de France (= United Protestant Church of France)
PKN Protestantse Kerk in Nederland (= Protestant Church in the Netherlands)
SEK Schweizerischer Evangelischer Kirchenbund (= Swiss Protestant Church Confederation)

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[8] On the ethics of care at the end of life see Leget and Kohlen, Chapter 5, this volume.

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